BLOOD & MARROW TRANSPLANT PROGRAM

AUTOLOGOUS TRANSPLANT PATIENT EDUCATION MANUAL
INTRODUCTION

Welcome to UC San Diego/Sharp BMT Program. Our goal is to provide you with an education manual that will be a resource and tool to help you and your family throughout the transplant experience. The content of this manual is designed to provide material on the transplant process, general information about medical procedures, supportive care and possible problems that might occur.

The Moores Cancer Center is an NCI-designated Cancer Center with a unique opportunity to provide specialized 'bench-to-bedside' personal care. An NCI or National Cancer Institute designation confirms that the Moores UCSD Cancer Center has established itself as a leader in cancer research and treatment. We are the only NCI-designated Cancer Center in San Diego. We are also one of 23 institutions that make up the National Comprehensive Cancer Network (NCCN) that represent the nation’s top cancer centers – coast to coast.

In addition, the Blood and Marrow Transplant Program is a joint effort between UCSD Medical Center and Sharp Healthcare. These two healthcare organizations have joined together to provide you with the latest in technology in bone marrow, stem cell and cord blood transplant services. The UCSD/Sharp Blood and Marrow Transplant Program is truly unique in San Diego County and committed to providing you with the best care and service for you and your caregivers.

We suggest that you share this manual with the caregivers who are supporting you throughout your transplant. Taking time to discuss the protocols and sharing your understanding with each other helps to fully understand the treatments, their purpose and your expectations.

It is important to understand that if your health condition changes at any time, your eligibility for transplant may be affected. Not all patients who are referred to our program are accepted as candidates for transplant. Our program does have a process in place to review such cases on an individual basis.

Thanks again for putting your trust in our team.

Edward D. Ball, MD
Program Director
THE HEALTH CARE TEAM

The health care team caring for you during your transplant consists of a group of experienced care providers with various skills and abilities whose focus is on your care. The members of the team are described below.

INPATIENT
Physicians/Doctors
The bone marrow/stem cell transplant/cord blood (BMT) doctors providing care consists of attending physicians, fellows, and consultants.

Although your primary attending physician is in charge of your care, we have other attendings that may alternate during your inpatient stay. Due to this rotation, you may be under the direct care of one of the team’s attending doctors. However, your primary doctor will be in contact with the team and will visit you while you are in the hospital.

The fellow is a doctor who has completed specialized medical training and is focused on caring for patients with cancer (hematology/oncology patients). These doctors will see you in the hospital everyday and make decisions regarding your care with the assistance of the attending and your primary transplant doctor to provide you with consistent quality care.

Our bone marrow/stem cell transplant doctors often work together with other doctors within the UC San Diego Health System. You may meet the consulting doctors sometime during your treatment if needed. Often, these specialists are requested by the transplant doctors to make a consult and offer suggestions for your treatment. Some of these specialists include skin, heart, kidney, lung and mental health doctors. Our doctors also network and consult with other national and world-wide medical centers and doctors.

Advanced Practitioners - Nurse Practitioner (NP) and/or Physician Assistant (PA)
The Advanced Practitioners on our team are specialized in bone marrow, stem cell, and cord blood transplantation. They follow your daily care and are trained to perform tests such as skin biopsies, lumbar punctures and bone marrow biopsies. They also work closely with the doctors and other members of the team to manage your care.

Inpatient Nurse
During your stay in the hospital, you will be cared for by specially trained BMT registered nurses who are also certified to administer chemotherapy. These nurses are responsible for meeting your daily needs which may include giving medications and teaching you on any of the necessary subjects for your treatment and discharge.
They work with the doctors and other members of the team to make sure you are receiving quality care, offer emotional support as needed, discuss treatment plans, and offer help with personal hygiene or meals and suggest a daily routine to best meet your needs.

Clinical Care Partner
The CCP is a trained nursing assistant who works closely with the nurse to make sure that all your basic needs are met each day. The CCP will help you with personal hygiene, changing your bed, assisting you with meals, and taking your vital signs. The CCP also plays an important role in providing you with personal quality care.

Clinical Social Worker
Your assigned social worker will help you before your transplant, during your hospitalization as well as after discharge. For further information, please refer to the section on Social Work Services.

Dietitians
A dietitian who specializes in transplant patients will closely monitor the amount of food you are eating. If you are having trouble eating or have special needs, the dietitian can provide helpful hints to improve your appetite. The dietitian is available to you throughout your hospital stay during daytime hours. Refer to Section 6 for further information on nutrition.

Hospital Unit Services Coordinator (HUSC)
You will meet the HUSC on your day of admission into the hospital. The HUSC works at the nurse’s station and is responsible for answering call lights, phones, and communicating your needs to the other staff members. He/she also assists in scheduling tests that you may receive while in the hospital and doctors’ visits you will have after discharge.

Pharmacist
Throughout your transplant, a pharmacist who is familiar with your treatment will manage the medications that you will be taking. The pharmacist works closely with your doctors and will monitor the use of medications during your transplant.

Physical Therapist
We feel that maintaining your strength helps you recover from your transplant and is an important part in the total healing process. Because, your white blood cells, red blood cells, and platelets will be low during your stay in the hospital, certain activities are limited. The physical therapist will help you in creating a daily exercise program that is safe for you. The physical therapist will monitor your strength to make sure you are staying as fit as possible and able to do things for yourself. The therapists are available during the day from Monday through Friday.
OUTPATIENT

Apheresis Team

The apheresis team includes a Medical Director, doctors, a Nurse Manager and specially trained registered nurses that collect your donor’s stem cells. They are available if you or your donor has questions regarding the apheresis schedule or procedure. Your cells may be collected at the Medical Center in Hillcrest or the Moores Cancer Center.

Advanced Practitioners – See Inpatient Team

BMT Coordinator

This is a specially trained transplant registered nurse whose role is to coordinate your care and tests after your attending doctor has evaluated you to be a transplant candidate. The coordinator stays in close contact with you throughout the entire transplantation process and is your link to the rest of the transplant team.

Case Manager (Clinic Nurse)

The case manager is a registered nurse who coordinates your pre-transplant care including clinic visits, inpatient or outpatient chemotherapy, laboratory work and other tests or procedures.

Clinical Trials

The BMT Clinical Trials group includes a manager, Clinical Research Associates (CRAs), and an administrative assistant. Research studies involving people are called “Clinical Trials” and are one of the most important ways of finding out new information leading to better treatment and management of cancer. If you decide to participate in a clinical trial the CRAs will work very closely with you, the doctors and nurses to make sure that clinical trial treatment plan is followed.

Data Management

The BMT Data Management staff includes a data analyst and two data managers. Medical information is collected and sent to the Center for International Blood and Marrow Transplant Research (CIBMTR) and the National Marrow Donor Program (NMDP). The data is used to study important questions and concerns in transplant and cancer care treatment.

Financial Manager

The UC San Diego Blood & Marrow Transplant Program has a manager and staff whose purpose is to serve as a liaison and resource for the financial needs of our patients. We accept Medicare, Health Maintenance Organization (HMO’s), and Preferred Provider Organizations (PPO’s) and have contracts with most major insurance companies. The financial team verifies transplant benefit coverage and coordination of benefits on every new patient and obtains authorizations for all transplant related services. The team is available if
you have concerns regarding your insurance coverage. Also, we encourage our patients to immediately notify the staff of any known changes to plan coverage or benefits.

**Infusion Center Nurse**

Before and/or after your transplant, you will need to come to the Infusion Center at the Moores Cancer Center as an outpatient for laboratory (lab) draws, **intravenous** (IV) fluids, blood products and medications. The specially trained registered nurses will carry out these tests for you and work closely with your doctor and coordinator to maintain quality care.

**Stem Cell Processing Laboratory (SCPL)**

The SCPL team includes a Medical Director, a supervisor and specially trained technicians that process and store the cells that are collected during apheresis or bone marrow harvest.
## Important Phone Numbers

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<td>My Physician:</td>
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<td>My BMT Coordinator:</td>
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<td>My Clinic Nurse Case Manager:</td>
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<td>My Social Worker:</td>
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<td>Other Members of my Healthcare Team:</td>
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**Thornton Hospital:**
- **(858) 657-7000**
- **3W Inpatient:**
  - **657-6390**

**Moores Cancer Center:**
- **Information Desk:**
  - **(858) 822-6146**
- **Infusion Center:**
  - **822-6294**
- **Multi-specialty Clinic:**
  - **822-6100**
- **Pharmacy:**
  - **822-6088**
- **(Refills):**
  - **(619) 543-6191**
- **UCSD (Hillcrest):**
  - **(619) 543-6222**
DIRECTIONS, TRANSPORTATION, AND PARKING

Directions:

Thornton Hospital:

**From I-5** - Exit on Genesee Avenue and go East. Turn right on Campus Point Drive. Shiley Eye Center is located on the left; Perlman Ambulatory Care Center and Thornton Hospital are located on the right. To get to the Moores Cancer Center, turn left on Medical Center Drive and follow it around Shiley Eye Center to Health Sciences Drive.

**From I-805** - Exit on La Jolla Village Drive/Miramar Road, and go West. Turn right on Genesee Avenue, then turn left on Campus Point Drive. Shiley Eye Center is located on the left; Perlman Ambulatory Care Center and Thornton Hospital are located on the right. To get to the Moores Cancer Center, turn left on Medical Center Drive and follow it around Shiley Eye Center to Health Sciences Drive.

Moores Cancer Center:

**From I-5** – Exit La Jolla Village Drive and head east. Turn left onto Regents Road. Turn left onto Health Sciences Drive. Park in the lot on your left, immediately before you reach the Cancer Center, or enter the circular driveway for valet service.

**From I-805** – Exit La Jolla Village Drive and head west. Turn right onto Regents Road. Turn left onto Health Sciences Drive. Park in the lot on your left, immediately before you reach the Cancer Center, or enter the circular driveway for valet service.

UCSD Medical Center – Hillcrest:

**From I-5**: Exit on Washington Street and turn left (East). Turn left on First Avenue, and then turn left on W. Arbor Drive. Drive past the Medical Center, directly into the parking garage at the end of W. Arbor Drive.

**From SR-163**: If you are coming Southbound, exit on Washington Street West. If you are coming Northbound, exit on Washington Street (which will take you eastward), and then make a U-turn so that you are headed West. Turn right on First Avenue, then turn left on W. Arbor Drive. Go past the Medical Center directly into the parking garage at the end of W. Arbor Drive.

Transportation:

*The Moores UCSD Cancer Center Shuttle:* Patients and caregivers may use the shuttle free of charge. For more information about shuttle schedule and stops go to: Cancer.ucsd.edu/PatientCare/Transportation, or call: (619) 726-6515.
Parking – Moores Cancer Center:
- Lots: $4 for first two hours, $1 for each additional hour, up to a maximum of $8. Visits of 30 minutes or less are free. Pay on foot at pay station near the northwest corner of Moores Cancer Center (accepts cash, validation tickets and credit cards) and exit through vehicle express exit. Kiosk is staffed 8 a.m. to 7:30 p.m.
- For Thornton pay on foot at pay stations near the entrance to Perlman Medical Offices or in the parking lot on Health Sciences Walk, and exit through vehicle express exit.
- Valet: $5 plus 50 cents for each additional half-hour, to a $10 maximum.
- All parking, including valet, is free for patients with a handicapped placard. If you do not have a placard, please contact your social worker.
- Radiation Oncology and Infusion Center patients can have their parking validated at no cost.

Thornton Hospital, Perlman Medical Offices, and Sulpizio Cardiovascular Center
For short-term parking, use lot P751, directly in front of Thornton Hospital or, the East Campus Parking Structure next to Sulpizio Cardiovascular Center. For valet parking, see the attendant in the driveway in front of Thornton Hospital.

East Campus Map
**BMT BASICS**

**Bone Marrow and Stem Cells**
Bone marrow is the soft, spongy tissue found inside the bone. Its goal is to form **blood cells**. All blood cells develop from immature cells called stem cells.

Stem cells develop into one of three following types of mature blood cells which enter into the blood stream:

- Red Blood Cells (RBCs)
- White Blood Cells (WBCs)
- Platelets

Some stem cells are also present in the blood stream; they are called **peripheral blood stem cells (PBSCs)**.
The term **Bone Marrow Transplant** refers to those transplants in which stem cells are removed from the bone marrow. When taken from the bone, it looks just like blood. If the stem cells are collected from the blood (peripheral blood), the correct term is **Peripheral Blood Stem Cell Transplant**. However, you may hear this shortened to stem cell transplant. You may also hear the term bone marrow transplant used for both types of transplants. Do not be confused by these differences.

**Clarification of terms:**

bone marrow transplant = peripheral blood cell transplant = hematopoietic cell transplant = stem cell transplant = blood cell transplant

The main source for most types of transplants due to improvements in collection and storage methods are PBSCs.

**Blood Cell Functions**

- **Stem Cells**, as mentioned above, are located in the bone marrow and make most of our body’s blood cells. They divide to become new stem cells, RBCs, WBCs or platelets.

- **WBCs** (also called leukocytes) are very important to our **immune system**. They help the body fight **infections**, viruses and other threats. There are many different parts of a WBC. Each one plays a specific role in destroying these “foreign” bodies. **Granulocytes** are part of the WBC that helps fight bacterial infections. **Lymphocytes** are another part of the WBC that helps the immune response.

  For example, when you catch the flu, there is an increase in the WBCs to help fight the infection.

- **RBCs** (also called erythrocytes) are cells that contain a protein called **hemoglobin**. Hemoglobin carries oxygen from the lungs to the rest of the cells in your body. A low RBC count is a condition called **anemia**. Someone who is anemic may feel weak, dizzy, short of breath and tired.

- **Platelets** (also called thrombocytes) are cells that help prevent bleeding. When you cut yourself, platelets help form blood clots to stop the bleeding at the site of the injury. A low platelet count (**thrombocytopenia**) increases the risk of bleeding of the gums, nose and other tissues. Unexplained bruising and **petechiae** (tiny red spots) can also be caused by a decrease in platelets. Refer to **Complications** in section 5 for further detail.

**Reasons for a Blood or Marrow Stem Cell Transplant (BM/SCT)**
The basic idea behind a BM/SCT is to allow high doses of chemotherapy and/or radiation therapy to kill rapidly dividing cells in the body like cancer cells. However, though these treatments are among the most effective weapons against many forms of cancer, they cannot
target only diseased cells. As a result, non-diseased cells that divide rapidly such as stem cells are also destroyed in the process.

Therefore “rescue” with transplanted bone marrow or stem cells enables the patient to produce new blood cells to replace those destroyed during treatment. It is a type of “transfusion” that replaces diseased or damaged bone marrow with new functioning stem cells.

In addition in allogeneic transplant, the new immune system may help prevent relapse through a mechanism called “graft versus malignancy” effect.

Stem Cell Collection
Before the time of transplant, medications will be given to you called growth factors (with or without chemotherapy) to make your bone marrow produce more stem cells than it normally does. This is called mobilization. These cells are released into your blood stream, collected through a process called “apheresis” (refer to section 3 for details) then sent to the Stem Cell Processing Laboratory where they are frozen (cryopreserved) and stored.

Bone Marrow Harvest
Bone marrow harvest is a procedure that is done in the operating room. After you (or your donor) are given medication to make you sleep (general anesthesia), one or two cuts are made into the skin at the back of each hip bone. Special needles with syringes are then inserted into the bone and marrow is collected. This procedure generally takes about 1 ½ hours. The cells are also sent to the processing laboratory and either frozen and stored or processed to be reinfused that day.

Engraftment
After your preparative regimen, the bone marrow or stem cells are reinfused and migrate back to their natural home (bone marrow). This is known as “engraftment” which means a full recovery of WBCs, RBCs, and platelets. Refer to section 5 for further details.

TYPES OF TRANSPLANTS

Autologous Transplantation
“Autologous” means from your self. In this type of transplant, you serve as the donor. For this kind of transplant to be successful, it is best for you to be in remission. That is, to demonstrate a response (chemosensitivity) to treatment you received prior to your transplant. It is important that your blood and bone marrow be disease free.

Syngeneic Transplant
The donor is an identical twin.
**Allogeneic Transplantation**
Allogeneic means the donor is a person other than the patient. Donor selection is based on shared genetic tissue typing with the patient known as Human Leukocyte Antigen or HLA typing.

HLA markers serve as a kind of genetic finger print which enables the body’s immune system to recognize its own cells. The genes occur in pairs, with one part of each pair being from each parent (mother and father). Therefore, the search for a matched donor begins with the immediate family. HLA typing is done using blood samples from the patient and the donors.

The donor is usually a brother or sister (sibling) or a parent or child which is rare. Once a sibling donor has been found, he or she is asked to donate, and bone marrow or stem cells are collected. It is important to mention that the donor’s supply of cells will be replenished as bone marrow constantly makes stem cells.

Once donor collection is done, the patient receives the preparative regimen assigned by the BMT doctor. After the regimen, the cells are returned as discussed above.

Allogeneic patients are also placed on drugs that suppress the immune system called **immunosuppressants** to prevent rejection of the donor’s cells which can create a problem called **Graft versus Host Disease (GVHD)**.

**Matched Unrelated Transplants (MUDs)**
This is a type of allogeneic transplant that is done when a related donor cannot be found. In this case, a very close HLA matched donor is found using the **National Marrow Donor Program** (NMDP) data base.

There are many donor centers in the United States, Europe and Asia who tissue type those who wish to become donors. These potential anonymous donors are typed, just as your relatives might be. The results are then placed in a data base with those of thousands of other possible donors. Successful unrelated transplants occur frequently today as many people share similar genetic backgrounds. There are also an increased number of donors enrolled in the NMDP which increases the chance to find an unrelated donor with a similar genetic type.

**Cord Blood Transplants – Used when an unrelated donor cannot be found.**
This refers to the blood stem cells from **umbilical cords**. Like bone marrow, umbilical cord blood is rich in stem cells. It is collected from the placenta and cord after a baby is born.
PREPARING FOR THE TRANSPLANT

Your Initial Visit (Consultation)
Your oncology doctor has referred you to one of our doctors to determine if you would benefit from a bone marrow or stem cell transplant.

During your first visit, your BM/SCT doctor will obtain details of your present medical condition(s) and medical history. Reports of your scans, biopsies, laboratory work, past and present treatments will also be reviewed at this time.

You will then meet with your transplant coordinator who will continue to work with you through your transplant process and follow-up care. Your coordinator is your “link” to the transplant team.

If you are feeling anxious or distracted, it is common to forget things. It is a good idea to bring someone with you to your first meeting as a lot of information will be discussed. Also, bring a note pad to write down questions that may come up before or after the meeting.

After your initial visit, your case will be discussed among our attending doctors and you will be placed on our list of patients waiting for transplant.

Housing
Most patients who are having transplants live in San Diego County; however, some patients do not. The transplant doctors have carefully analyzed the travel distances and time to Moores Cancer Center and Thornton Hospital to make sure that patients have access to specialized medical care. Therefore, patients who live in San Diego County are allowed to remain in their own homes. If a patient lives outside of San Diego County, the patient and their caregiver will need to make different arrangements. You may have a family member or friend who lives in San Diego County and would be willing to allow you to live with them during the transplant process or other arrangements such as a hotel, an apartment, the UC San Diego Bannister Family House or Mesa Housing on campus (if available). Resources are available on the following website: www.joeshouse.org

Pre-transplant Evaluation
Once authorization for your transplant has been obtained through your insurance carrier, and before the actual transplant process begins, you will need to have several tests taken. These tests will help to decide if you are eligible for transplant. The results will also be used as a baseline to measure your progress through your hospitalization. Any tests that are not normal may need further discussion and investigation.

The tests, along with a reassessment of your disease, are usually done after you have completed your pre-transplant treatment. Your coordinator will assist in scheduling and explaining the tests with you including:
• **Blood tests** which assess how your organs are functioning and for certain infectious diseases

• **Urine tests** that measure kidney function

• Test for the **heart** may include:
  1) Electrocardiogram (EKG) which measures the heart’s rhythm and function.
  2) Echocardiogram is an ultrasound of the heart. It measures the heart’s muscle strength and is used to look at parts such as valves and chambers.
  3) Multiple-gated acquisition scan (MUGA) which also evaluates heart muscle function.

• Tests for the **lungs** (pulmonary) include:
  1) Chest x-ray
  2) Pulmonary function test (PFT) which involves inhaling and exhaling into a machine to measure lung function.

• A **skeletal survey** is a series of x-rays of the long bones in the body (arms, legs, spine and skull) to see if lesions are present. *This test is only done on patients with multiple myeloma.*

• A **bone marrow biopsy** is an outpatient procedure to obtain samples for testing the bone marrow function. After medication is given to numb the site, a needle is inserted into the back of the hipbone and a small amount of bone marrow is removed.

• A **Computerized Tomography (CT Scan)** is a special x-ray technique that produces images of cross-sections (slices) through your body. This enables your doctor to view the inside of your body at different angles.

• **Magnetic Resonance Imaging (MRI)** uses a magnetic field and radio-waves to take multiple cross-section images of your body. These slices are then put together into a three dimensional image. This shows the contrast between different types of body tissue in great detail.

• **Positron Emission Tomography (PET scan)** is a procedure in which a small amount of radio-active sugar is injected into your veins. A scanner then is used to make detailed pictures of the areas inside the body where the sugar is used. Because cancer cells often use more sugar than normal cells, these pictures can be used to find active cancer cells in the body.

• Decayed teeth and gum disease can cause serious infections in transplant patients. If possible, it is important to have a complete **dental exam** before your transplant. All dental work should be completed at least 14 days before the beginning of your preparative regimen.

• You will also meet with your clinical social worker to discuss non-medical aspects of the transplant

• **Attend the autologous patient education class that is offered once a month**

**Alternative and Complementary Therapies**
With growing public interest in alternative and complementary therapies comes an increased need for accurate information to be made available for patients and families to
help in making informed choices for safe, effective treatment options. If you have questions on the different therapies, please discuss with your physician.

**The Consent Process**

Once all of your exams have been completed and reviewed by your transplant doctor, you will meet with your coordinator who will provide you with a **treatment calendar**. This is a useful tool to use to remember the appointments that have been scheduled for you. The coordinator will also discuss the transplant process in detail.

It is a good idea to review any written materials you received at your initial visit. Again, we encourage you to ask questions and that a family member and or friend come with you to this visit. You will need to identify someone to help you as you may need someone to drive you to some of the appointments such as your catheter placement appointment. Explanations of various tests will be provided before you are asked to sign a consent form. You will also have an appointment with your transplant doctor to discuss the consents and answer any questions you might have.

**Central Venous Catheters**

All patients receiving a bone marrow or stem cell transplant will need a central venous catheter. There are many different types of central catheters and the one chosen for you depends on the type of transplant you will be receiving.

Autologous transplants require you to have an **apheresis catheter**. This catheter is chosen because it works with the machine that collects your stem cells. It is also used to give you medications, IV fluids, blood and platelet transfusions, chemotherapy, and the bone marrow or stem cells. The catheter is also used to take blood samples. The catheter will remain in place throughout the entire transplantation process.

![Apheresis Catheter](image)

This is a simple outpatient procedure that is performed by our Interventional Radiology Team at Thornton Hospital. The doctor will discuss the procedure and, after you have signed a consent, you will be given medication to put you to sleep (sedation). After the catheter is inserted, you will have a chest x-ray in the recovery area to make sure the catheter has been placed properly. Due to the sedation, you **will need a driver to take you home**. You will not be allowed to take a bus or taxi.
Catheter Care
The nursing team in Interventional Radiology will instruct you not to bathe or shower for four days after your catheter is placed as the site must be kept clean and dry. However, you may sponge bath during this time. After the four days, you may resume your bathing or showering. To prevent moisture from collecting under the dressing, you will be taught how to cover the entire catheter site with a plastic bag and tape.

You will need to have the dressing on your catheter changed everyday during the first four days, then weekly. Dressing changes will be done in the Infusion Center by the nursing staff as they are responsible for the care and maintenance of your catheter. Your coordinator will schedule the appointments for you. If your dressing becomes wet or soiled, please notify the Infusion Center or your coordinator.

Exit site care
Your catheter will have two separate tubes (lumens) that extend from the exit site. The tubes will have a clamp on them that should remain closed when the catheter is not in use. Also when the catheter is not in use, the tubes are flushed weekly with a medication to prevent clots.

Monitoring the site
You will be asked to inspect your catheter site every day and to monitor your temperature twice a day for signs of infection. If you experience any of the following symptoms, please contact a member of the health care team immediately.

Signs of infection include:
- pain
- redness
- tenderness
- pus around the site
- fever

It is also important to report shortness of breath and/or swelling in your arms, hands or chest and any color changes of the skin on your arm.

Stem Cell Collection – (Apheresis)
Apheresis is derived from a Greek word meaning to take away. The process takes between 2-5 days for approximately 4-6 hours each morning and is usually performed on an outpatient basis. Rarely, some cases are done in the hospital. It is recommended that someone drive you to your scheduled appointments.

The procedure will be explained to you by a doctor and you will be asked to sign a consent. You will then be connected by your catheter to the apheresis machine. The machine is a blood separator and a small amount of blood (no more than a cup) is removed through one
lumen. It goes through the cell separator called a centrifuge which separates platelets, RBCs and WBCs. The bag with the WBCs contains the stem cells. The remainder of your blood is returned to you through the second lumen of your catheter.

Keep in mind, this is a painless procedure and you may relax in the chair or bed while watching television, movies, or you may wish to read. A specially trained nurse will be with you throughout the process.

During the time you are undergoing apheresis, daily lab tests are done to count the number of stem cells collected. Each patient has a targeted number of cells to be collected for transplant. The apheresis staff will be in contact with you daily and will notify you when your goal has been met.

After the stem cells are collected, they are transported to the Stem Cell Processing Laboratory. The cells are processed under germ-free (sterile) conditions. During the process, the amount is reduced by removing the liquid that does not contain cells. A small amount of preservative is added and the stem cells are frozen in a special way called cryopreservation and stored. On the day of your transplant, the frozen cells are delivered to the floor in a container that contains dry ice (liquid nitrogen) by one of the processing laboratory technicians and signed-off to the nurse who is assigned to you. The transplant procedure is discussed in further detail in section 5.
PREPARATIVE REGIMEN

The preparative (conditioning) regimen is the high dose chemotherapy and/or radiation therapy that patients receive prior to their transplant. The primary goal of this treatment is to destroy any cancerous cells throughout the body more effectively than may be possible through other types of treatment. The regimen may take place over 2-8 days.

Your doctor and coordinator will discuss which regimen is best for you. You will receive a copy of the administration schedule along with chemotherapy educational handouts. The material can be placed in this section to refer to as needed. The inpatient team will also review the regimen with you after you are admitted to the hospital for your transplant.
HOSPITAL ADMISSION

What to Bring to the Hospital
Preparing for your hospital admission can make your stay much more comfortable. You will be staying in a single room that has limited storage space, so light packing is suggested. Your friends and family can bring additional supplies during your stay if needed. Remember that your immune system will be compromised (immunosuppressed) while in the hospital, so keeping your room clean is important.

Note: There is a possibility that you may be admitted into a semi-private room for the first 1-2 days depending upon bed availability.

Here are some helpful tips to remember while you are packing:

Clothes
We do provide hospital gowns and pants. However, you may wish to bring your own clothing. Please bring clothing that is comfortable and opens in the front, so that your central catheter can be easily accessed (i.e. button down top). Please wear clothing that does not require your line to be unhooked. We discourage unhooking your central line from the IV tubing in order to prevent infection, even while you are showering. We want you to have a clean change of clothes after you shower each day. You will need to make arrangements for your caregiver to wash your clothes because we do not provide laundry service. Space is limited, so only bring enough clothing for five days. We also want you to wear something on your feet while walking on the floors in your room. We provide booties; yet, you are welcome to bring your own slippers. Having a hat, scarf or wig will provide you with warmth as well.

Bedding
We attempt to change your bedding everyday usually while you take a shower. You may want to bring your own pillow (not feathered), several clean, colored pillow cases and a freshly laundered quilt or spread. Keep in mind that pillowcases and spreads will need to be laundered by your caregiver.

Toiletries
Again, we do provide you with items for you for your personal hygiene; but, you may bring your own new and unopened soap, shampoo, lotions and make-up. Keep in mind that your skin will be sensitive due to the treatment and perfumed products should be avoided. Do not bring a toothbrush or toothpaste because a special mouth-care regimen will be started on admission. Your nurse will teach you about how to specially care for your mouth on your admission day. Be sure to trim your fingernails and toenails prior to admission.
**Items to Bring**
* pictures of loved ones and special places
* eyeglasses
* electric razor
* portable radio/DVD/CD player
* inspiring posters
* music
* new makeup
* new nail file
* slippers
* scarves/hats/wigs
* new deck of cards
* extra pillow (not feathered)
* favorite blanket or quilt (washed)
* notepad/journal
* books and magazines
* books on tape
* craft project
* crossword puzzles, Sudoku, word search
* videotapes
* hard candy for your transplant day
* a large calendar
* telephone/address book
* lap-top computer (wireless access card)

**Things Not to Bring**
* money
* toothbrushes or dental floss
* mechanical razors
* nail clippers
* scissors
* contact lenses
* pets
* jewelry
* fresh flowers
* dried flowers
* live plants
* no moss around the base of silk flowers
* medications as medicine will be provided
* wallet

Please note: Jewelry is discouraged as IV fluids may cause fingers to swell, so your rings maybe tight and hard to remove.

Please tell your family and friends that gifts are welcome but you cannot have fresh fruits, fresh flowers, dried flowers, or any artificial flowers containing moss. More appropriate gifts are pictures, balloons, books, tapes, or games.

**Electronic Equipment**
During your stay at UCSD, we will make every attempt to see that you are as comfortable as possible. All of the rooms on the BMT unit have a color television and cable. Some rooms are equipped with a VCR. There are videotapes available for your use; but, you may want to bring your favorite videos for entertainment.

*Note on lap-top computers: Thornton Medical Center and the Cancer Center both have free WIFI access.
Mail
If mail is sent to you, please make sure that your full name and room number is on the letter or package. Mail can be sent to:

UCSD THORNTON HOSPITAL
(Your name)
3 West, Room ____
9300 Campus Point Drive
La Jolla, Ca 92037

Daily Hospital Routine
The mornings are usually the busiest part of the day. This is the time when doctors and other members of the team including nurse practitioners, pharmacists, the charge nurse and the social workers visit each patient and discuss their progress. We call this “rounds”. Also, tests are done and treatments are given. Throughout the day, you may see other members of the staff including housekeepers, dietitians, and physical therapists.

A nurse and CCP will be assigned to you on a daily/nightly basis. Remember, the attending physicians do rotate. Whoever is “on-service” at the time you are in the hospital is in charge of your daily care. The team does communicate your plan of care and needs as they arise with your primary transplant doctor on a regular basis.

You probably will have expectations of the transplant team; and, we have expectations of you. Expectations are part of your plan-of-care and were created to help you maintain your strength and prevent infections and problems from occurring. Your care plan will be discussed with you daily; and, we encourage you to ask questions as needed.

Meals- everyday at breakfast you will receive a standard menu for the following day. On this menu you will select what you want for breakfast, lunch, and dinner. Snacks are also provided during the day per your request any time between 7:00 am and 7:00 pm by dialing extension 77007 on your room phone. On the day of your admission, your nurse will call the kitchen and order your first day meals. A dietary consult order can be placed for you and the dietician can meet with you to discuss your dietary options. The dietician will also discuss with you the importance of obtaining enough nutrition and calories during your transplant.

Around the time of your admission, you will be placed on a special diet that is intended to lower the risk for getting food related infections. Please see the attached Low Microbial Diet Guidelines.

Fluid Balance
It is very important that we monitor your intake and output (I&O) as well as complete physical assessments daily. Fluid balance is important in preventing dehydration, fluid
overload and maintaining electrolyte balance (high or low sodium, magnesium, potassium, calcium and phosphorous).

We will place collection containers in the toilet so that your output can be measured. Please use these containers as it will help the staff in determining your care needs. We will also weigh you daily to monitor your fluid balance and nutritional status. Because a large amount of intravenous fluid is given to you during your conditioning chemotherapy, you will be weighed between 10am and 12pm daily.

To maintain electrolyte balances, you may receive oral or IV replacements based on your morning laboratory values.

**Medications**

When you are admitted to the hospital, we ask that you bring a list of your medications and the dosages with you. It is helpful for the admitting practitioner to have an accurate account in order for you to continue those medications while you are in the hospital. Please do not bring any medications with you. At times, certain medication swill be stopped or held until you leave the hospital.

After your transplant, you will be put on new medications that will help prevent different types of infections (bacterial, viral and fungal). In addition, other medications will be ordered that help support the transplant process. All the medications are important for you to take. They will be discussed with you and your caregiver regularly during your hospital stay and after you go home.

Once you are discharged, you will receive a new medication list called a Med Action Plan. This list and will include new medications along with any that you were taking before your admit. Keep in mind; these may have been changed during your hospital stay.

All medications must be picked up at a UC San Diego Health System pharmacy before you are discharged and for the next 2-3 months. This is done to prevent any interruptions with your medication care.

It is important to remember that if you have any questions or concerns regarding your medications that you speak to your transplant coordinator, advanced practitioner or doctor as soon as possible. It is not unusual for you to be on some of the medications for 6-12 months.

**Vital Signs**

Vital signs (heart rate, blood pressure, temperature, respiration rate, oxygen and pain levels) are taken at least every four hours around-the-clock or more if necessary. The doctors will perform a head-to-toe assessment on you in the morning before or during “rounds”. The RN’s also perform an assessment in the morning and evening and
communicate any changes to the team of physicians. The nurses will draw your blood at least once a day, usually between 11:00 PM to 12:00 midnight and will give you the results around 6:00 AM each day.

**Hygiene**
We will instruct you on how to perform oral hygiene with a soft toothbrush (provided by the unit) and toothpaste. Use salt water to rinse your mouth four times a day prior to brushing your teeth. Good hygiene, such as frequent hand washing and daily skin cleaning promotes good health. Cleaning your skin every day helps to remove bad bacteria that may cause diseases (especially while your immune system is depressed). Hibiclens is an antiseptic, antimicrobial skin cleanser that helps to prevent infections. The inpatient team will provide you with instructions for bathing and showering when you are admitted. As mentioned above, you will be expected to shower daily and you will be expected to put on a new gown or clothes each day.

**Exercise**
During your hospital stay it is important that you exercise daily. Your doctor might order a consultation from a physical therapist. Physical therapy can provide safe exercises that are specific to your needs. There are different strength exercise bands that can be provided to help you stretch and strengthen your muscles. Staff will let you know when it is okay for you to walk in the hallways with or without a mask.

It is also important to keep your lungs in good shape. We will provide you with an **incentive spirometer** which is a plastic device that you will use every three hours during the day to help expand your lungs to **prevent problems** such as **pneumonia**. The nurse will teach you how to use it as well as other types of deep breathing exercises.

**Visitor Guidelines**
We know that your friends and family are important to you; and we encourage visitors. However, we also want to protect you from **microorganisms** (bacteria, fungus, and viruses) that can cause infection. So, we have created the following visitor guidelines:

Thornton Hospital does not have formal visiting hours. If your visitor arrives after 8:00 PM, please instruct him/her to enter the hospital through the Emergency Department. Visitors over the age of 18 years old can stay with you overnight. Cots may be available for one person to stay over night with you. The cots must be folded and set to one side of the room between the hours of 7:30 AM and 10:00 PM. Visitors are not allowed to sleep in the hospital lobby or the hospital atrium.

We do not validate for parking on the unit. Visitors can get their ticket validated on the day you are discharged.
All visitors must stop at the nurse’s station before entering your room. The staff will briefly screen your visitors for infection. We will not allow someone to visit if he/she has a cold or contagious infection. Visitor guidelines will be posted in your room and it is important that you and the staff discuss them with your visitor(s).

Proper Hand-washing
Turn on the water and wet hands, dispense soap and lather hands, and scrub around the wrists and between fingers and fingernails for at least 15 seconds, rinse and dry with paper towels, discard paper towels in the trash. The faucet in the hallway has foot pedals to operate them. Each and every patient’s room has its own anti-bacterial hand gel just inside the door.

Children are allowed to visit; however, they must be supervised at all times and are not allowed to play in the hallways. They must not show any signs of infection. Infants and children who have recently received the oral polio vaccine (OPV) which is a live attenuated vaccine should not visit the transplant floor for 4-6 weeks. Household members of transplant patients should receive the inactivated polio vaccine (IPV).

While in the room, visitors are not allowed to use the patient’s bathroom, phone, sit on the bed or eat in the patient’s room. There are bathrooms and pay phones located in the hospital that are available for their use.

Visitors may bring food from home with a written order from the doctor and after the dietitian has met with them and discussed proper food preparation and handling. The food must be well-washed, cooked, and then immediately wrapped and refrigerated. It should be in a single serving container and may be microwaved only ONCE prior to eating.

It is important for visitors to understand that you may be tired or not be feeling well. Therefore, they may need to limit their visits accordingly.

UCSD, Thornton Hospital provides a tobacco-free environment. Smoking is only allowed in posted smoking areas.
THE TRANSPLANT

Day Zero – Your New Birthday
Day zero is the day you will receive your stem cells either from bone marrow or peripheral blood. The days leading up to day zero are referred to as “minus days” and the days after your transplant are “plus days”. Each day, staff will write the day (minus or plus) of your transplant on the board in your room.

On day zero, your assigned nurse will re-infuse your marrow or stem cells. This procedure takes place in your room and it is similar to a blood transfusion. You will be given medications to prevent a possible reaction(s) that may occur due to the preservative in the stem cells or bone marrow. These medications may make you sleepy during the procedure. Your vital signs will be checked often and you will be closely observed by your nurse.

If your cells arrive frozen, the nurse will thaw them in a heated water bath at your bedside and infuse them through your central line into your blood stream. The cells are preserved with a chemical called dimethylsulfoxide (DMSO) that protects the cells during the freezing and thawing process. This preservative will cause your room to have an odor for a day or two. The odor has been described as a garlicky or canned corn smell. You may also have a bad taste in your mouth, or feel a tickle in your throat or experience coughing during the infusion. Sucking on candy or mints may help lessen the taste.

Following the transplant, your blood counts will be monitored daily. You will be informed of your results and transfusions of blood and platelets will be given as needed. The nurse will tell you about special precautions to take when your blood counts are low. A calendar is provided at the end of this section to keep track of your daily counts while you are in the hospital.

Engraftment
The time for your bone marrow to engraft and start to work and make new white cells, red cells and platelets differs depending on the type of transplant you receive. The nurses and doctors will tell you when to expect your new cells to grow on their own. Please remember that every patient is different and the time of engraftment varies for each person.

Complications
The first few complications discussed here will be early side effects that can be caused by the preparative regimen.

Some common side affects that people have within the first few days of treatment may be nausea, vomiting, diarrhea, or mouth sores. Bleeding, infection and/or hair loss may occur during the first 1-2 weeks after treatment. Damage to the reproductive organs often results in long term infertility. Severe or long term damage to organs such as kidneys, liver, or lungs occurs much less often.
The transplant team will see that the correct measures are taken to prevent or decrease any discomfort. Also, depending on the complications that you may experience, you may be transferred to a unit that has specially trained staff that can provide a higher level of care such as heart monitoring and/or specialized medicines. However, you will still be seen daily by the physician or advanced practitioner on the BMT team.

**Nausea and Vomiting**
Drugs called **antiemetics** are used to prevent and treat nausea and vomiting. These medications have improved recently; however, not all people respond to medicines the same way. Be sure to let the team know if you are having any nausea or vomiting so changes to your medications can be made.

**Diarrhea**
Diarrhea can also be common in people receiving chemotherapy. **Antidiarrheals** can also be used to slow down diarrhea or cramping. Be sure to cleanse your anal area after each bowel movement. This will help prevent any skin breakdown or infection.

**Mouth Sores**
Mouth and throat discomfort, or **mucositis**, can occur 4-8 days following some preparative regimens. Good oral hygiene is very important during your transplant and will help limit the amount of discomfort and prevent mouth infections. Medications can be applied to numb the area (**topical anesthetics**) or intravenous **narcotics** can be given to relieve any mouth or throat pain. Mucositis normally improves when the white blood cells start to engraft.

**Bleeding**
Chemotherapy causes a decrease in the platelet count. These are the blood cells responsible for helping the blood to clot. A low number of platelets, or **thrombocytopenia**, may cause a patient to bleed or bruise more easily than usual. Platelet transfusions may be given if the platelet counts drops too low. During this time there are a few precautions that can be taken to help prevent bleeding. These include:

- keeping your skin and lips moisturized as dryness may lead to cracks and bleeding
- sexual intercourse is not advisable if a platelet count is less than 50,000
- only use an electric razor
- do not go barefoot; wear slippers or shoes at all times
- do not use nail clippers
- drink plenty of fluids to avoid constipation and avoid straining during bowel movements
- do not use rectal thermometers, suppositories, or enemas
- do not use aspirin or products containing aspirin
- use only a soft toothbrush, do not scrub gums too hard or use floss
- no contact sports
**Infection & Neutropenia**

Infection is the most common side effect of transplantation. This is due to the destruction of white blood cells (that help fight infection) by chemotherapy. Infections can come from the environment, but the most common source of infection is bacteria originating from the patient’s own body. Medications will be used to prevent and treat infection and special precautions will be taken to help avoid infection.

Neutrophils are a type of white blood cell and are an important part of how your defense system fights infection. An absence or low count of neutrophils (neutropenia) makes a person more likely to get an infection. The degree of neutropenia is based on the absolute neutrophil count (ANC) which is a measure of the number of neutrophils present in the blood. A normal ANC is about 1,500. An ANC of less than 500 is defined as neutropenia and significantly increases the risk of infection. Nadir is the word used when your WBC count is at its lowest.

The ANC is calculated using the number of neutrophils (“segs” or segmented cells) plus the bands (young neutrophils) which represents a percentage of the total number of white blood cells (WBC).

The following is the formula for calculating the ANC:

\[ \text{ANC} = (\text{Segs\%} + \text{Bands \%}) \times \text{WBC} \]

For example, a CBC lists the:

- WBCs as 4.6K (“K” stands for 1000) = 4,600
- Segs = 40
- Bands = 5

\[ 40\% + 5\% = 45\% \text{ or } .45 \]

\[ \text{ANC} = .45 \times 4600 = 2070 \]

It is recommended that all blood and marrow transplant patients follow the guidelines listed below to prevent infection:

- follow a neutropenic diet (refer to Section 7 - Nutrition)
- bathe or shower daily with antibacterial soap
- good oral hygiene with mouth care to be done as prescribed
- cleanse rectal area after each bowel movement
- have an incentive spirometer in your room and use it every 3 hours while awake
- avoid contact with people who have colds, flu, chicken pox, or any other contagious disease
- avoid plants, fresh flowers
- take antibiotics/antivirals/antifungals as prescribed
- take granulocyte colony stimulating factors (G-CSF) as prescribed

At any time when a blood marrow or stem cell transplant patient develops a fever over 100.5F, the “fever” protocol will be started by the inpatient RN including:

- Drawing blood for cultures from your central line and arm
- Collecting urine, sputum and central line area samples
- Ordering a chest x-ray
- Starting intravenous antibiotics
- Notifying the practitioner
- Provide comfort measures if needed (i.e. a fan, cool or lukewarm bed bath, Tylenol)

It usually takes 1-3 weeks for the white blood cell count to be high enough for a patient to be discharged from the hospital following an autologous stem cell transplant. Discharge date will be determined by the attending physician.

**Hair Loss**
Most preparative regimens will lead to temporary scalp and body hair loss (alopecia) one to two weeks after the start of treatment. Some patients cut their hair short or shave their heads before hair loss begins. Scarves, hats, or wigs can be used until hair grows back. Hair normally grows back within 3-4 months after the transplant.

**Relapse and Secondary Malignancy**
Some patients will experience a relapse of their disease even after a transplant. The risk of forming another type of cancer, caused by the chemotherapy and/or radiation has been documented in a small number of patients. If either of these occurs, you can talk with your doctor about treatment options.

**Organ Toxicity**
There is a possibility that high dose chemotherapy as well as a number of other medications required during transplant can cause a decrease in the ability of your lungs, heart, kidney or liver to function. These organ toxicities are usually mild as well as temporary and reversible.

**Infertility**
Sterility is a potential complication of high dose chemotherapy. The likelihood of infertility depends on the patient’s age, gender, type and amount of chemotherapy received. Although most patients who undergo a transplant will be infertile afterwards, those who do not wish to become pregnant should not assume they cannot. The normal options of avoiding unwanted pregnancies need to be practiced.

Fortunately, there are options available to couples who wish to have children after a transplant. Adoption or medically-assisted reproduction technologies can be explored if this applies to you. Feel free to discuss options with your doctor, coordinator or social worker. Refer to the Resource Guide for further resources.
SOCIAL WORK SERVICES

If your doctor has recommended a bone marrow, stem cell, or cord blood transplant, you may be feeling overwhelmed and somewhat frightened by what may lie ahead. You may have concerns about your job, finances, family, friends, and your own survival. You may also feel a great sense of hope about the future. There is support available to help you and your family.

Clinical Social Worker
You will meet with your licensed clinical social worker during one of your initial visits to UC San Diego. Your clinical social worker will interview you and answer non-medical questions about transplant. You will also be given information on hospital services and community resources. Many insurance companies require that a social worker meet you, and they may ask for information from your social worker.

During your treatment, your social worker will monitor the effect that this treatment is having on your emotional and social well-being. She will also be available to give you and your loved ones the support you may need. This might include counseling, community resource referrals, and support group information. If you or your loved one would like psychotherapy, check your insurance plan’s mental health benefits. Out-patient psychological services may be available to you or your loved ones at Moores Cancer Center, perhaps even without insurance coverage.

To help you during your stay at Thornton Hospital and to help prepare for your return home, your clinical social worker will often talk with your doctor, nurses, and other members of your health care team. All communications, of course, are confidential.

How should I prepare for my transplant?
We encourage you to bring family members and/or friends to your appointments and tests as they will have a large part in your care. Before the transplant and during the in-patient hospitalization it is not required to have a family member with you at all times. After you are discharged from the hospital, you are required to have someone with you full-time to assist you with your daily care and transportation needs. If possible, we encourage you to have a primary caregiver with help from other caregivers. Plan for a minimum of at least one month. This requirement may be longer depending on your health status and the type of transplant you have. Transplantation requires a serious commitment from you and your caregivers.

Advance Health Care Directives (Durable Power of Attorney for Health Care, Living Wills) are written documents where you state the kind of medical care you would want in the future. This is based on your values and personal beliefs. There are two primary parts to an Advance Health Care Directive. One is to pick a person with whom you can discuss your wishes, and who will carry out your wishes if you cannot speak for yourself. The second
part is to write down under what conditions you would no longer want certain medical
treatments. When making this decision it is important to consider quality of life.

At UC San Diego, we recommend that all patients have Advance Health Care Directives. You will be asked at the time of your hospital admission for a copy of your completed Advance Health Care Directive for your medical record. If you do not have a completed directive, you may obtain a form from your social worker.

What about relationships?
This experience, most likely, has changed your perspective on life. Your priorities may have changed as well as what you value. Your illness may also have affected the feelings and perspectives of the people around you. Sometimes people may treat you differently, like you are fragile or delicate. Talking about your feelings will help other people understand. Help them understand that although you may need assistance, it is important for you to participate in life as much as possible.

The transplant experience may be stressful for your family members. Roles often change within the family. The well spouse or support person may need to take on added responsibilities or learn new tasks. There may be financial concerns (ask your clinical social worker if any resources are available for you and your family). Family members and caregivers are encouraged to ask for help from others. We find that people are eager to help and may not be able to anticipate your family’s needs. They may be waiting for you to ask!

What about my children?
It is very important to be honest with your children and encourage them to ask questions and talk with you. While some parents may feel that keeping their cancer diagnosis a secret is protective, children may actually feel excluded and confused by the secrecy. Let your children know that they are allowed to ask questions and that you will answer them as honestly as you can. This should begin before your transplant and continue throughout the transplant process.

When you discuss your medical condition with your children, it is important to be age appropriate. You may give simple information to a small child and more complex information to a teenager. Since you know your children the best, gauge your answers accordingly. Take the time to listen to their successes, problems, and fears. Encourage them to draw, talk, or act out their feelings. Children have vivid imaginations, and what they imagine may be more frightening to them than reality. Books are available to help you discuss issues with your child. Professional help is also available.
**Tips for Coping:**
Everyone experiences some emotional reaction to their illness and transplantation, although individuals may experience them at different times and in different ways. There are many ways to cope with emotional and practical changes.

Suggestions for patients include:
- Write down your questions and ask them as frequently as needed. You may also want to write down your feelings.
- Sometimes your memory can be short and unpredictable. Write down information during your transplant.
- Request contact from a former transplant patient with whom you can talk and receive support.
- Do the best you can to make each day count.
- Take one day (or one moment) at a time.
- Read inspirational books by survivors.
- Manage stress through deep breathing, visualization, meditation, or other relaxation techniques.
- Focus on something that puts you in control, such as your attitude or communicating with your health care team.
- Before you are discharged home, be sure that you and your support person clearly understand what follow-up care is necessary.
- If you have a chaplain, rabbi, or minister, they are welcome to visit you in the hospital. Hospital chaplains are available if requested.

Suggestions for caregivers:
- Ask other family members and friends for help caring for the patient, your family, and you during the transplant process.
- Be realistic about your limitations. Get enough sleep, eat properly, and take time off for yourself. You will be a bigger help to the patient if you are healthy and calm rather than sick and overwhelmed.
- Be prepared for possible changes in the patient’s behavior. The medications and stress may cause the patient to become depressed, anxious, or angry. Speak with the doctor if you have concerns. At the same time, understand that your loved one needs you more now than ever before. Your help is not only welcomed, it is absolutely essential.
- Don’t be shy about tracking down the medical staff to get help or have your questions answered. You’ll feel better knowing that staff is aware of issues that you’ve noted.
- Finally, if you are feeling helpless, remember that the moral support you provide is often the “best medicine” the patient can receive.
Discharge Home from the Hospital:
It is an exciting time when the patient goes home from the hospital. However, it is normal if the patient and/or caregivers have some fears or concerns. There may be worries about being away from the security of the hospital setting or close contact with the hospital staff. Be patient with yourself and others as these are valid feelings.

Going home has been your main goal during your hospital stay. Now your goal is to continue to take care of yourself and regain strength.

Suggestions for Patients:
- Do not try to resume all of your previous responsibilities immediately. When family and friends offer to help, let them!
- Keep stress factors to a minimum. Let a member of your medical team know if any specific things are bothering you.
- If children have behavioral changes when you go home, allow time for routines to stabilize. Let teachers and friends know what is happening so that they can provide help if needed.
- Friends and relatives may be unsure of what to say or do, especially if they have not seen you since your transplant. Bring them up to date on your condition, feelings, and hopes for the future to the degree that you are comfortable. Help them know how to be supportive to you.

Returning to Work or School:
You should inform your employer or school staff that the usual recovery time after a transplant is six months. This may be longer depending on how quickly you recover and what type of transplant you’ve had. It may be possible for you to work at home or your office for short periods of time during off-hours. If you are in school, you might hire a tutor or take classes online. Since there are important medical considerations, any decision to return to work or school should be discussed with your doctor. If you have concerns about returning to work or school, you can discuss them with your social worker.
GOING HOME

Discharge Planning
Planning for your discharge from the hospital begins on your day of admission. Due to the advancements made in the bone marrow and stem cell transplantation, patients are being discharged from the hospital earlier. The discharge process can be overwhelming due to the amount of information, anxiety and other emotions. Therefore, it is important for you, your caregivers and the transplant team to address your needs early in the course of your hospitalization.

Transplant team members will provide you with the information about your post-transplant care. It is important to ask questions and take notes. We recommend bringing this manual with you into the hospital so we can refer to it during your stay.

Some common guidelines regarding discharge planning and home care are listed below:

- A clean home
  Your home should be thoroughly cleaned at least a few days before you are discharged due to your risk for infection. Special attention should be given to the floors, carpets, bathtubs, sinks, and toilets. Have the filter on your ventilation system changed to decrease dust and dirt.

- You are not allowed to clean!!!
  Let your family and friends clean for you and please stay out of the room they are cleaning. Cleaning should be done on a regular basis.

- Do not share!!!
  Use your own utensils, towels and toothbrush. Clean bath towels and linens regularly in HOT water.

- Plants and Flowers
  Limit the number of plants and flowers in your house. DO NOT take care of them. Allow your caregiver to water and re-pot them. You should avoid caring for plants and gardening for six months and during periods of substantial immunosuppression. Once you are able to garden, you must use garden gloves and we recommend wearing a mask.

- Pets
  You can keep your pets in your home and you CAN pet them. Remember to wash your hands afterwards. DO NOT clean litter boxes, bird cages, fish bowls, etc. DO NOT handle animal excretions for at least 1-year post-transplant.
**Mouth or Oral care**
Thorough mouth care is important to maintain healthy gums and teeth. You will need to rinse your mouth with Normal Saline for a full minute four times a day then gently brush your teeth, gums and tongue with a fluoride toothpaste. If bleeding occurs or if the toothbrush causes pain, use a foam toothette instead.

If you are regularly flossing your teeth, you may continue to do so but only do it once a day. Do not floss if it causes bleeding or increased pain, if your platelets drop below 50,000 and/or ANC is less than 1,000.

Keep your lips moist using a lip balm or Vaseline. Avoid mouth rinses containing alcohol or hydrogen peroxide. Acidic, salty, spicy, hot and coarsely texture foods should be kept at a minimum.

Continue to see your dentist twice a year. Notify the transplant team before your first dental visit after transplant.

If your mouth feels dry, rinse your mouth with Normal Saline before and after meals as needed, chew sugar-free gum, avoid tobacco and alcohol or ask your doctor about artificial saliva.

**Nutrition**
Nutrition is very important during this time. It is important that you have an adequate intake of calories, protein, vitamins and minerals to support your growing immune system. As mentioned above, you will remain on the Low-Microbial Diet for up to three months after your transplant or as determined by your doctor.

Changes in taste, dry mouth and possibly some nausea may decrease your interest in eating. During this time, small frequent meals with snacks and the use of nutritional supplements (Carnation instant drinks, Ensure, Sustacal, and Slim Fast) may be helpful in supplying enough calories and nutritional intake.

**SKIN CARE**
**Sun Exposure**
You should avoid direct sun exposure. Your skin will be sensitive to the sun because of the high-dose chemotherapy and/or radiation.

Wear sunglasses to protect your eyes, always wear a sunscreen of at least 30SPF and wear a hat and long sleeves as well as long pants. Cover as much skin as possible. Light colored clothing is the best.
Examine your skin daily for signs of:
- Bruising, rash, swelling or redness
- Shower daily and use a moisturizer. Use a mild shampoo and conditioner on your hair and scalp. After bathing, pat skin dry – DO NOT RUB. Pay special attention to drying skin folds, including genital and rectal areas. Use a rubber mat in the tub to avoid slipping. Use mild soaps without perfumes and deodorants.
- Cover your central venous site when showering.
- Wear comfortable loose clothing.

More on Infection Prevention
Even though your white blood cell count may be in the normal range when you are discharged from the hospital, your immune system may not function normally for as long as one year.

Here are some guidelines to help you stay free from infections:
- **Wash hands frequently.** This includes you, your family and friends. Please refer to “Visitor Guidelines,” section for hand-washing guidelines. Make sure hands are washed after touching an animal, before and after meals, before preparing food, after using the toilet and before taking medications. Have paper towels handy to dry your hands.
- **Avoid large crowds and people with infections or colds for at least 1 month.**
- Take your temperature at the same time once or twice a day, more often if you are not feeling well.
- **Avoid** swimming in oceans, lakes, public pools, rivers, or hot tubs for three months. If you have a central venous catheter, this is also prohibited.
- If you MUST change a diaper on a baby, please wear disposable gloves and wash your hands immediately after changing the diaper.

Immunizations
Talk to your doctor before receiving any immunizations. Avoid infants and children who have been recently vaccinated with oral polio. Tell your doctor if you have been exposed to such child. If you have children, talk to your child’s pediatrician about your child’s immunization schedule and inform him/her that you are a transplant patient.

Exercise
Be aware that you will tire easily after the transplant process. Be patient with your body. You will need to rebuild your strength and endurance slowly. As your body adjusts to an increase in activity, you will find that you have more energy.

Prioritize your tasks and activities. Plan your day and include time for exercise and rest. Regular exercise is important to improve muscle tone and strength. Walking or riding a bike are good ways to exercise.
Preventing Bleeding
After your discharge from the hospital, you may still be at risk for bleeding. Please ask your nurse or doctor if this is a risk for you. A platelet count of less than 50,000 and the need for frequent platelet transfusions will put you at risk for bleeding.

Use these following precautions:
- Use an electric razor.
- Avoid contact sports.
- Avoid heavy lifting.
- Do not go barefoot. Always wear slippers or shoes.
- Drink plenty of fluids to avoid constipation.
- Avoid sharp kitchen utensils or tools.
- **Do not use rectal thermometers, suppositories or enemas.**
- Do not have sexual intercourse if your platelet count is less than 50,000. See the following section on sexual activity for more recommendations.
- **Do not use aspirin or products containing aspirin (it causes bleeding) such as:** Alka-Seltzer, Anacin, Bufferin, Ascriptin, Aspergum, Bayer and Bayer Decongestants, BromoSeltzer, Congesprin, Dristan, Ecotrin, Excedrin, Fiorinal, Midol, Nuprin, Percodan, Sine Off, St. Joseph’s Aspirin, Four Way Cold Tablets.

Sexual Activity
Your sexual desire may be decreased following your transplant. In most cases this is only temporary and normal desire will return. Try to keep an open mind about the different ways to feel sexual pleasure. Many couples have different ideas of what is "normal" sex. There may be times when intercourse is not possible. Those times can provide you the opportunity to learn new ways to give and receive sexual pleasure. You and your partner can help each other reach orgasm through mutual caressing and stimulation. At times, just cuddling can be enough. Do not deny yourself different ways of expressing, caring, and feeling alive, just because your usual routine has been disrupted. Open communication between you and your partner is an important part of resuming sexual activity.

If you are having a hard time coping with issues such as body image, desire, response and your identity as a man or woman, please let your nurse, doctor or social worker know.

Here are some guidelines to follow:
If your platelet count is below 50,000, be gentle to avoid bleeding and infections. Sexual intercourse is not advisable if your platelet count is less than 50,000. Practice cleanliness and safe sex. Also, remember you will become tired more easily, so do not over-exert yourself. You and your partner should use a condom for three months following your transplant. It is advisable to avoid oral sex until your mouth is completely healed. It is also advised to refrain from anal intercourse for six months following transplant.

Kissing is fine, but continue to use common sense. Good oral hygiene is important. If you or your partner has a cold, fever, open sore on the mouth-DO NOT KISS each other.
Masturbation is okay, just remember to maintain good hygiene and to BE GENTLE. To prevent trauma to this area, use a water-soluble lubricating jelly, such as a KY Jelly, Replens, or Lubrin. You can purchase these items at your local drugstore. Never use Vaseline, as it can cause infections and decreases the effectiveness of condoms. Condoms are also recommended to prevent infection.

**Women**

Although infertility is possible, birth control should be used. Six months after transplant, you should visit your gynecologist. Keep track of any menstrual cycles you have and any signs of menopause. These signs include hot flashes, mood swings, flushing and difficulty sleeping. When you visit the gynecologist, discuss the pros and cons of hormone replacement therapy. If hormonal therapy is not an option for you, an endocrinologist may be able to relieve these symptoms using non-hormonal therapy.

Chemotherapy can cause your vagina to be dry. Douching with chemical products is not recommended. These products can destroy the natural bacteria in the vagina and cause infection to occur. Douching with water is okay. Sexual aids such as vibrators are fine to use. Just remember to be gentle. Clean the vibrator after every use.

**Men**

Although infertility is possible, birth control should be practiced. You can have a sperm count done to determine if you are sterile. Chemotherapy can cause your semen to appear brown or burnt orange with the first few ejaculations. If you continue to have brown discharge, pain, or inability to attain or sustain an erection consult your physician. Also, if you are unable to sustain or obtain an erection and you feel that your interest in sexual activity has not returned, consult your doctor. Your testosterone levels may be low due to chemotherapy. Your testosterone may need to be replaced.

**Infertility (Men & Women)**

Infertility generally follows high-dose chemotherapy or radiation treatment. Sperm or egg banking should be done well before admission for transplantation if this is a concern. An interruption in the menstrual cycle is common in women, and, long-term estrogen replacement may be recommended. However, fertility may recover in a small percentage of both men and women. Birth control measures are recommended while you are taking medications related to transplantation.
Calling the Transplant Team
If you do get an infection, your doctor should be notified immediately. The following is a list of signs and symptoms that should be reported:

- A temperature greater than 100.5 degrees F.
- A persistent cough.
- Shaking chills with or without fever.
- Persistent nausea and vomiting.
- Persistent pain.
- Diarrhea, constipation or pain with bowel movements,
- Shortness of breath.
- Excessive fatigues, irritability, or lethargy.
- Chills that occur after your central line is flushed.
- Redness, swelling, drainage, or tenderness at your catheter site.
- Pain, burning, or increased frequency with urination.
- Sores in the mouth or throat.
- Any sore or wound that does not heal.
- Swelling in any area after injury.
- Unusual vaginal discharge or itching.
- Development of a rash on your skin.
- Presence of blood when vomiting.
- Blood in your urine or stools (red or black).
- Persistent nausea, vomiting, constipation, or diarrhea.
- Exposure to chicken pox.
- Sudden bruises or hives.
- Headache that persists or any sever headache.
- Blurry vision.
- Persistent dizziness.

Call 911 in an emergency situation.
The Bone Marrow Transplant doctor can be reached by calling the page operator at (858)657-7000.
CLOSING REMARKS

We hope you have found the information in this manual a valuable resource. Please refer to it as needed, bring it to the hospital when you are admitted and to your clinic and infusion center appointments. Keep in mind we are available to answer questions that you may have about your plan of care and the transplant process.

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Additional copies of this manual can be located on-line at

RESOURCE GUIDE

American Cancer Society
800-227-2345
www.cancer.org
Brochures on cancer and treatment options; support groups.

Blood & Marrow Transplant Information Network (BMT InfoNet)
888-597-7674
www.bmtinfonet.org
Books, recommended reading, monthly newsletter, and on-line support network.

Cancer Care, Inc.
800-813-4673
www.cancercare.org
Publications, counseling services, and financial aid.

Cancer Legal Resource Center
866-843-2572
www.disabilityrightslegalcenter.org
Information and resources on cancer-related legal issues, including insurance, health care, employment, family, finances, and government benefits.

fertile HOPE, Fertility Resources for Cancer Patients
855-220-7777
www.fertilehope.org
Education and support for cancer patients dealing with fertility issues.

International Myeloma Foundation
800-452-2873
www.myeloma.org
Education, support, and research updates.

Kids Konnected
800-899-2866
www.kidskonncetected.org
Free programs for children who have a parent with cancer.

Leukemia and Lymphoma Society of America
800-955-4572 or 858-277-1800 (San Diego/Hawaii Chapter)
www.lls.org
Publications, support services, and financial aid.
National Bone Marrow Transplant Link (BMT Link)
800-546-5268
www.nbmtlink.org
BMT information, publications, and links patients with BMT survivors. “Survivor’s Guide for Stem Cell Transplant” can be ordered or downloaded.

National Marrow Donor Program (NMDP)
800-627-7692
www.marrow.org
The NMDP has a data bank of volunteer marrow donors.

OncoLink
www.oncolink.com
Information on cancer types, treatment, coping, resources, and reading lists.

Patient Advocate Foundation
800-532-5274
www.patientadvocate.org
Help with insurance and healthcare access problems, attorney referrals.

Planet Cancer
www.planetcancer.org
An international community of young adults with cancer (ages 18-40). The site offers information, entertainment, and support.

The Bone Marrow Foundation
800-365-1336
www.bonemarrow.org
Financial aid, education, resources, and emotional support.

**Personalized Websites:**
Caring Bridge
651-452-7940/651-789-2300 (Customer Service)
www.caringbridge.org
Free, private, personalized websites for easier communication with family and friends.

Care Pages
888-852-5521
www.carepages.com
Free personal, private web pages that help family and friends communicate when someone is facing illness, both in English and Spanish.

For additional resources, please contact your BMT social worker.
GLOSSARY OF TERMS

Advanced Healthcare Directive
An advance directive identifies a person whom you have chosen to make health decisions for you if you are unable. It assigns someone you trust to make choices in whatever situation arises-based on the stated preferences in your living will.

Allogeneic Transplant
The use of a donor's hematopoietic cells to restore bone marrow function and blood cells after receiving high dose chemotherapy. Hematopoietic cells are obtained from a genetically matched individual who is usually a brother or sister, but may be an unrelated volunteer donor.

Alopecia
Hair loss.

Anemia
A low number of red blood cells. Symptoms may include fatigue, weakness, pale skin color, dizziness and headaches.

Antibiotic
A drug used to prevent or fight infection from bacteria.

Antidiarrheal
A drug that helps relieve diarrhea.

Antiemetic
A drug used to relieve nausea and vomiting.

Antifungal
A drug used to prevent or fight infections from fungi.

Antineoplastics
Drugs used to treat cancer, refer to Chemotherapy.

Antiviral
Drugs to prevent or fight viral infections.

Apheresis
The collection of immature hematopoietic cells from the blood. This is accomplished using a blood separating machine that sorts the blood cells.
Aspiration
The removal of fluids from the body by suction.

Autologous transplant
A transplant in which the patient’s own bone marrow or stem cells are used.

Bacteria
Living organisms that can be seen only under a microscope and that can cause infection.

Biopsy
The removal of a small amount of tissue from the body to be studied under a microscope in order to determine the presence or absence of disease.

Blood cells
Cells that make up the blood, including red blood cells, white blood cells, and platelets.

Blood count
A lab test to determine the number of cells in blood.

Blood transfusion
To replace blood cells in the blood stream when there is a deficiency of a particular type (e.g., platelets, red blood cells).

Bone marrow
A spongy substance, which fills the hollow spaces in bones. This is where blood cells (red, white and platelets) are produced.

Bone Marrow Biopsy
A procedure used to obtain a sample of bone marrow from the hip bone for microscopic examination.

Bone Marrow Harvest
The collection of immature hematopoietic cells from the hip bones. This procedure is performed in the operating room.

Catheter
A hollow tube inserted into a body cavity (i.e. vein, bladder, etc.) to drain fluid or instill medications, fluids, etc.

Central venous catheter
A small, soft plastic tube inserted into the large vein above the heart through which medication can be given and blood drawn.
Chemotherapy
A drug or combination of drugs used to kill cancer.

Conditioning regimen
The combination of chemotherapy drugs and/or radiation used to prepare your body for bone marrow transplantation.

Cryopreserve
A process by which something (such as cells, sperm or embryos) is frozen to preserve it for later use.

Day zero
Day zero is the day of your bone marrow or stem cell transplant.

Dehydration
Abnormally low body fluids. Symptoms include flushed, dry skin, decreased urine output, thirst, weight loss, dark urine.

Diuretic
A drug which increases the elimination of water and salts (urine) from the body.

DMSO - Dimethylsulfoxide
A chemical preservative used when stem cells are frozen.

Donor
An individual who will donate hematopoietic cells for another individual. Types of donors include siblings (brothers/sisters) and unrelated volunteers. There are varying degrees of genetic matching between a donor and a recipient. The donor and recipient may be fully matched and partially matched. One type of donor is a haploidentical donor. A haploidentical donor is an approximately 50% match.

Durable Power of Attorney
Refer to Advanced Healthcare Directive.

Edema
The accumulation of fluid in parts of the body causing swelling.

Eligibility
A series of tests of organ function (heart, liver, kidney and lungs) that determine if you are healthy enough to undergo a transplant.
**Engraftment**
The time when the transplanted cells begin to manufacture new cells in the bone marrow (white blood cells, red blood cells and platelets).

**Gastrointestinal tract**
The digestive system, including the mouth, esophagus, stomach and intestines.

**Genes**
Structures that transfer hereditary information from cell to cell.

**Graft-vs.-host disease (GVHD)**
A common complication of allogeneic transplants. It occurs when the new marrow (the graft) recognizes the recipient (the host) as foreign and sends out lymphocytes to attack it. It can involve the skin, liver, gastrointestinal tract and other organs.

**Granulocytes**
A category of white blood cells that contain granules in their cell body.

**Granulocyte-colony stimulating factor (G-CSF, Neupogen)**
A medication that makes the bone marrow produce more stem cells.

**Growth factor**
An agent that stimulates growth of cells.

**Hematopoietic stem cells**
Hematopoietic means blood. Hematopoietic cells are blood cells. Immature hematopoietic cells, often called stem cells, can divide and mature into white and red blood cells or platelets.

**Human Leukocyte Antigen (HLA)**
The human leukocyte antigen system is a group of markers on the surface of your immune cells. The human leukocyte antigens are inherited. These markers are used to find a donor within your family or from the registry of volunteer donors.

**Hemoglobin**
That part of the red blood cell that carries oxygen around the body. A low hemoglobin may indicate a low number of red blood cells, or anemia.

**High-dose chemotherapy**
The treatment of disease through very high doses of anti-cancer drugs also referred to as the preparative regimen.
**Hydration therapy**
Intravenous fluids given to make sure the kidneys are functioning properly.

**Immune**
A state of adequate protection against certain infections or foreign substances.

**Immune system**
A group of organs, cells and other substances in the body that help fight disease.

**Immunosuppressants**
Medications given to weaken the immune system to prevent graft versus host disease.

**Immunosuppressed**
When the body's immune system is weakened and less able to fight infection and disease.

**Incentive Spirometer**
A small breathing device that is used to help prevent infections in the lungs.

**Infection**
The increase and invasion of disease producing organisms within the body.

**Inflammation**
Swelling, sometimes due to infection.

**Infertility**
The inability of a couple to achieve a pregnancy.

**Informed consent**
Your formal authorization to the hospital to perform transplant procedures. They are written in medical terms with detailed descriptions of the risks and side effects associated with BMT including potential long-term complications.

**Intake and Output (I&O)**
A measure of the amount of fluids you take in and the amount of all body fluids put out.

**Intravenous (IV) infusion**
Delivering fluids or medicine directly into the bloodstream through a vein.

**Living Will**
Refer to Advanced Health Care Directive.

**Low microbial (bacterial) diet**
A diet to decrease the risk of getting a food related infection.
Lumbar puncture (LP)
Technique used for removing small amounts of the fluid that bathes the brain and spinal cord. This fluid is tested for the possible presence of cancer cells as well as bacteria and other substances.

Lumens
Lines or tubes attached to a surgically placed catheter.

Lymphocytes
The white blood cells which form antibodies necessary for immunity to specific diseases.

Matched unrelated donor (MUD)
A type of allogeneic transplant using a donor from the general population who is not related to the patient but who is a very close HLA match.

Microorganisms
A microorganism can be a bacteria, virus, protozoa or fungus. Microorganisms cause infections in individuals with low white blood cell count or who are taking immunosuppressants (medications that weaken the immune system).

Mobilization
A process to increase the number of immature hematopoietic cells in the blood. By mobilizing (moving) the immature hematopoietic cells from the bone marrow into the blood, these cells can then be collected from the blood. Mobilization can be accomplished using high dose chemotherapy and/or a hormone that stimulates the bone marrow to make more hematopoietic cells.

Nadir
When the WBC is at its lowest.

Neupogen
Trademark name of the drug that makes the bone marrow produce more stem cells.

Neutropenia
Lack of white blood cells.

Peripheral blood stem cells (PBSCs)
Stem Cells that circulate in the blood stream.

Petechiae
Tiny pinpoint red spots on the skin or in the mouth, which indicate a low level of platelets.
Physical therapy
Provides intervention to restore or maximize the physical abilities of patients of all ages. The focus is to provide patients with the means to maximize functional independence.

Platelet
One of the main components of blood that produces clots to seal up injuries and prevent excessive bleeding. Also called thrombocyte.

Preparative regimen
The chemotherapy or radiation therapy given before transplant.

Radiation therapy
Treatment using high-energy radiation, as from x-ray machines.

Red blood cells
Cells that carry oxygen to all parts of the body. Also called erythrocytes.

Side effects
Reactions to drugs that are usually temporary and reversible. They do not relate to drug effectiveness.

Sitz Bath
A device that is used to clean around the rectal area.

Stem cells
Young blood cells found in the bone marrow, from which all other types of blood cells develop.

Syngeneic Transplant
A transplant from an identical twin.

Thrombocytopenia
A low platelet count. A low platelet count increases the risk of bleeding.

Topical
Applied to the skin.

Transfusion
Administering blood cells to minimize the symptoms of anemia or platelets to reduce the risk of bleeding.

Umbilical Cord Transplant (Cord Blood)
Transplant using cells from a newborn’s umbilical cord.
**Pasteurized**
Exposed to an increased temperature for a time long enough to destroy certain microorganisms that can produce disease or spoilage.

**Vascular access device (VAD)**
A long, narrow tube that is surgically placed into a large vein leading directly to your heart.

**White blood cells**
A variety of blood cells that help fight infections. Also called leukocytes.